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ABSTRACT

Based on the work of a task force of sixty-eight professionals (from medical and other related occupational fields) who met to define the role of the consumer in the improvement of the quality of his own health care, lists of positive directives for consumer action are presented under each of the following categories: access to health care, compliance with health care instruction, continuity of health care, and the outcomes of health care. A second set of lists focuses on the role of the consumer in overcoming barriers to quality health care, barriers relating to communications, cultural patterns, and cost. The appendixes, covering a major portion of the document, include the explanation of the origin of the conference and the charge, development of the plans, all conference addresses, and the evaluation. (BM)

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ED150269

The Role of the Consumer in Assuring Quality Health Care

June 1973

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Produced by a working conference of health care providers and consumers

Introduction

From 16 states they came. Sixty-eight persons with a common purpose: to begin to explore appropriate ways the American consumer can improve the quality of health care he receives.

The sole objective of the task force was to produce this document. It is intended to mark the beginning of a long journey to true involvement in health care by the consumer.

Many of the participants were themselves providers of health care. Each of them affirmed that the consumer roles suggested in this publication are indeed attainable and desirable.

The consumer roles listed here are not all-inclusive. They are meant to be considered, refined, added to and then implemented.

The task force participants were divided into eight workgroups, each to consider the consumer's possible roles in one of the following: access to health care, process of health care, compliance with health care instructions, continuity of health care and the outcome of health care. Also considered was the role of the consumer in improving communications and overcoming barriers to quality health care such as inadequate communications, lack of understanding of cultural patterns and cost.

Following are the consumer roles listed by this landmark task force.

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[For an explanation of the origin of this conference and the development of plans, see Appendix I, "Invitation Package," pages 75-88; Appendix III, "Welcome Address," pages 101-104; Appendix V, "Charge to Task Force," pages 111-113, and Appendix VI, "Energizing Session," pages 115-118.]

access

access

The consumer has a right to access to health care regardless of race, creed, religion, sex or ability to pay. The health care system must exist for the benefit of consumers; therefore, consumers must have the major voice and control in setting policy regarding access to the health care system. Both consumers and providers share the responsibility for improving access to health care.

- We, the consumer, require that a viable information and education component be developed within the health care system.

- We insist that the education for health workers include emphasis on how ethnic, geographic, socioeconomic, cultural, racial and other factors affect access to health care and provider attitudes.

- As consumers and providers, we need to develop an understanding of the differences between "access to health care" and "access to medical care." (Refer to figure one.)

- As consumers and providers, we must have a better knowledge of resources, the relationships between resources and how to use them most effectively.

- We, the consumer, demand that the provider give us understandable information regarding our health status.

- We must advocate that education and communications systems of the provider meet our language and cultural needs.

- We must understand the value of preventive as compared to curative health care.

- We demand that the health care system be coordinated so that all resources are used to improve access to health care, including resources such as public schools and public information media.

- School health programs, because of their unique relationships with children, should be used as the entry point into the health care system.

- As consumers and providers, we must establish better interaction so that both groups can better understand the reasons persons seek or do not seek health care.

access

The consumer must demand the establishment of a specific process within the health care system to identify potential consumers, to educate consumers, to bring consumers into the health care system, to involve consumers and to maintain the health of consumers.

- We, the consumer, demand that the health care system develop adequate outreach activities.

- We advocate the development of clear, distinct entry points to the health care system.

- We must exert pressure to redirect the health care system to focus on prevention of illness rather than on acute care.

- We encourage a better distribution of financial risk for catastrophic illness among consumers, providers and third parties.

- We must be informed about the "fee-for-service" method of payment and options to that method. The fee-for-service method does not meet the needs of all consumers, and we demand that more options be developed.

- We demand that the health care system place more emphasis on primary care and be better coordinated to avoid multiple entry points and confusion.

- We recognize that mechanisms must be established within the health care system to receive and process complaints to bring about adjustments responsive to our needs.

- As consumers and providers, we must work together to develop adequate transportation and communications systems so that they no longer present problems and barriers to access.

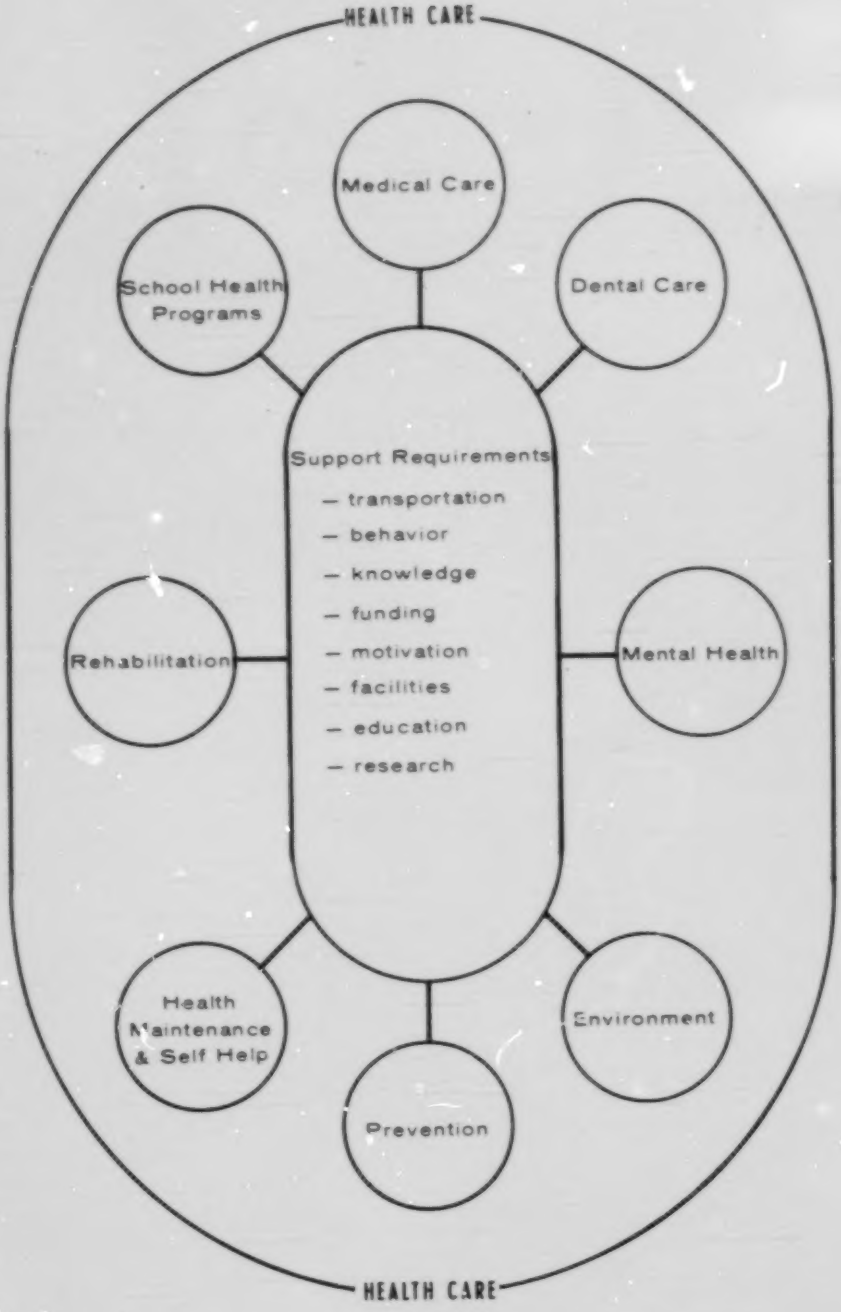
HEALTH CARE
Medical Care
School Health Programs
Dental Care
Support Requirements
– transportation
– behavior
– knowledge
– funding
– motivation
– facilities
– education
– research
Rehabilitation
Mental Health
Health Maintenance & Self Help
Environment
Prevention
HEALTH CARE

Figure 1

Consumer input and provider input can be synthesized to provide the optimum in quality health care and its implementation. These components can be effective only when both consumer and provider recognize, allow and accept the input of one another. All consumers have expertise about themselves and their environment which is not recognized and utilized by health care providers.

- Consumers must become involved in the development of educational curricula for health care providers.

- Consumers should advocate the development of "Health Rights" (analogous to "Legal Rights") information which can guide and stimulate the consumer's involvement in his own health care. (For example, exploration of choices available, alternatives, etc.)

- Consumers should share control in health organizations.

Consumer and provider communication of knowledge, training, and information that influences attitudes, behaviors, and social responsibility is essential to achievement of quality health care.

- Consumers should advocate the provision of health education programs in educational institutions commencing with elementary school and continuing throughout the educational system.

- Consumers should direct legislative attention to health education using those resources that are available (e.g., require all community health-related agencies to give top priority to health education and departments of health to give health education equal priority with environmental sanitation and public health nursing).

The consumer should have an active and well-defined role in the planning, identification and implementation of quality health care within the community through policy-making and evaluation.

- In view of the fact that qualifications for selection of policy-makers prevent equitable consumer participation, consumers should be active on policy-making and regulatory boards at all levels (state, local, national). These boards will use health professionals in a consultative role.

- Consumers must organize a system of evaluating health care to ensure appropriateness, effectiveness and efficiency.

The effectiveness of "people power" is directly related to their political and legislative "clout." System changes at all levels must be implemented through organized consumer effort.

- Consumers should bring together existing organizations interested in health care; i.e., free clinics, health rights, health councils, comprehensive health planning organizations, regional medical programs and voluntary organizations.

- Consumers should form organizations which contain large blocks of votes and elected representatives, as divisiveness of the present political system prevents consumer unity.

compliance

Lack of motivation can prevent the achievement of compliance with health care and treatment instructions. The consumer and provider of health care must be motivated to take an active interest in their roles in this *two-way* process. Assuming the consumer has access to provider services, the major concepts included under motivation are of prime importance in order that the consumer may develop the ability to solve the remaining stated problems.

- Consumers should identify a natural leader in the community to develop a consumer organization. Consumers should identify funding to compensate this leader.

- Through this organization, consumers must identify local health care problems.

- The consumer organization must integrate providers at the appropriate time to assure cooperation in helping to meet the needs of the neighborhood.

- Through the consumers' efforts in establishing such channels of communication, a health education process will be realized that will begin to show the consumer the need for compliance.

- The provider community must be approached by representative members of the consumer group to discuss the problems of lack of provider time and interest in sharing information and understanding about the patient's own health problems in order to achieve compliance.

- Consumers and providers must develop mutual regard and trust. When this is achieved, the maximum level of compliance can be obtained.

compliance

The inability of the provider and the consumer to speak together in mutually understandable terms can obstruct the consumer's willingness to comply with health care or treatment instructions. In addition, the lack of recognition of different cultural patterns on the part of the providers can hamper compliance. Providers often do not recognize different levels of consumer understanding.

- The consumer must be willing to tell the provider that he does not understand what is being said.

- The consumer must make the provider aware of any cultural differences that may affect the consumer's ability to comply with his health care instructions.

When the provider does not meet the consumer's total needs–as seen by the consumer–compliance may be difficult to achieve. Providers must consider the consumer's needs as the consumer sees them.

• The consumer must demand explanations from the provider when treatment is being prescribed that does not give direct relief for the consumer's perceived problem. (For example, the patient has an upper respiratory infection with painful throat and cough. The provider treats the ear infection he found on examination and seemingly ignores the presenting problems.)

compliance

When the provider does not realize the consumer's ability to understand and follow instructions, lack of compliance is frequently the result. Financial or social conditions may be additional factors that prevent effective compliance.

- The consumer must inform the provider of any conditions that hinder his ability to comply.

- The consumer must demand from the provider the necessary information to understand and comply with his medical treatment instructions.

- The consumer must have the opportunity to work out the treatment with the provider.

continuity

Health care for consumers must be individualized to each person's needs for the effective perpetuation of health care.

- The consumer should advocate the humanistic delivery of services in the context of his personal history and culture.

- The consumer should require the development of a personal and ongoing plan for his health maintenance.

- The consumer and the provider should share responsibility for the development of the plan to maximize the chance of success.

- The consumer assumes a major personal responsibility for carrying out a plan that is both desirable and understandable.

- There should be shared participation between the consumer and the provider(s) for the consumer's simplified lifelong comprehensive health record.

continuity

The consumer can follow his own personal and ongoing plan for health maintenance if communication is clear and the consumer understands his responsibility for the continuity of his health care.

- The consumer must ensure that the plan is expressed in understandable language and form.

- The consumer must have the opportunity to express his problems in his own terms and on his own level.

- The climate must be conducive to a balanced dialogue between consumer and provider.

- The consumer must advocate that an opportunity be provided for additional information at appropriate intervals.

- The consumer should advocate that health workers be prepared and available to function as a communications channel between the consumer and the provider.

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continuity

Health care delivery methods must offer individuality, comprehensiveness and quality to ensure continuity of health care to every consumer.

- The consumer should advocate the development of a prepayment mechanism to finance appropriate health care systems, thus removing the financial barrier to continuity.

- The consumer should advocate the development of incentives, including financial, to encourage both the consumer and the provider to ensure the continuity of good health.

- The consumer must encourage the organization of providers and facilities in such a manner that health care services are sufficiently convenient to encourage provider-consumer contact.

- The consumer as a member of the health care team has the right to expect use of the team concept when appropriate to the resolution of his specific problem(s).

continuity

Health care education is essential for the consumer to assume responsibility for his health needs as well as to participate in continuity of his health care.

- Consumers should receive education in the norms of growth and development.

- Consumers should receive education in the management of day-to-day care of minor illnesses, emotional and physical.

- Consumers should receive education in emergency medical care procedures.

- Consumers should demand information about ways to enter the health care system.

- Consumers should demand information about the availability of health care systems.

- Consumers should demand information about how they can participate in the use of health care systems.

- Consumers should receive education about when to seek health care.

continuity

A comprehensive and coordinated system of medical records should be developed to assure continuity of care.

- Consumers should advocate problem-oriented medical record systems. These records should be available and made understandable by the provider to the consumer.

- Consumers should demand that the medical records remain confidential.

- Consumers should advocate the development of a simplified lifelong consumer health record for which the consumer is responsible.

outcome

The ideal outcome of health care is the maintenance of and restoration of the patient to his highest possible level of function within his chosen life style. The consumer must accept active personal responsibility for health maintenance.

- The consumer must obtain health insurance.
- The consumer must respond to signs and symptoms of illness–the earlier the better.
- The consumer must learn and practice good health habits.
- The consumer must choose a portal into the health care system.

outcome

The degree of satisfaction with the outcome depends directly on the extent of congruence between the actual results and the expectations of the parties involved (consumer and provider). The consumer must be reasonably informed about "good" health and medical outcomes.

- The consumer must be made aware of sources of accurate health information.
- Every consumer should take a first-aid and/or a medical self-help course.
- Consumers should promote health instruction in the schools.
- Consumers should encourage consumer health education.
- Consumers should ask health providers, without hesitation, about what constitutes good health.
- Consumers should insist that programs of early detection and prevention be linked to evaluation and medical follow-up.

outcome

Each individual consumer must enter into the process of his own health and medical care, its planning, implementation and its monitoring, through intelligent interaction with the members of the provider community, to assure that his own goals are not lost sight of in the delivery of health care services. The consumer needs to know what resources and alternatives exist in seeking health care.

- The consumer must assume the responsibility to establish a relationship with a primary health care agent.

- The consumer must assume the responsibility to ask health providers, without hesitation, about what constitutes good health.

- The consumer must assume the responsibility to contact health agencies.

- The consumer must assume the responsibility to contact information referral organizations.

- The consumer must assume the responsibility to participate in volunteer health activities.

- The consumer must assume the responsibility to tour hospitals and other health care facilities.

- Consumers, as a group, have at least three tools to exert influence on the provider community: legislation, other purse-string controls, and membership on boards of health institutions, health councils and health planning groups.

outcome

A mechanism should be available to the consumer for selecting the health facility that will render the best outcome. Consumers should devise means to influence the quality of community health services.

- The consumer should locate the nearest emergency service.
- The consumer should know the ambulance, fire and police telephone numbers.
- The consumer should establish a relationship with a primary health care agent.
- The consumer must promote community action towards improved access to and availability of health care services.
- Consumer participation in comprehensive health planning is a means of effecting quality "outcomes" of health care.

outcome

The setting of goals of care is a joint responsibility (consumer and provider), but the consumer must recognize that the expertise in the technical details relative to health and medical care is the responsibility of the health professionals. It is the responsibility of health providers to assure quality medical care through peer review and other mechanisms; however, quality standards and performance assessment should be published so that the public and not just peer group is aware of outcome measures.

- Consumers should keep a health diary.
- Consumers should advocate a problem-oriented medical record.
- Consumers should ask questions if they do not understand the provider. Consumers should insist on an answer.
- Consumers must agree to release former health records to the consumer's current provider.
- The consumer must insist on continuity of health records.
- The consumer must follow through with health care instructions and report any complications or adverse reactions to medication or treatment.
- Consumers must be completely informed before being asked to consent to any medical procedure.
- Provision for overcoming language barriers, including jargon, must be arranged jointly by the consumer and provider.

outcome

Providers and consumers need to work together to devise and promote a more immediate, continuous and responsible two-way feedback system regarding health care.

- Consumers must insist upon adequate explanation after diagnosis and medication.

- Consumers should openly express satisfaction or dissatisfaction with care received.

- Consumers should advocate the publication of reports of health care facilities and standards of care.

- Provision for overcoming language barriers (including jargon) must be arranged jointly by the consumer and provider.

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communications

Improved communication depends on education at all levels. Identification of barriers can direct educational efforts and focus. Consumer-oriented status groups, such as community and health councils, are essential in consumer education. The consumer must have a basic knowledge of health and the health care system so that he can know resources, utilization, rights of care and ways to evaluate that care. The education must be provided in a language understandable to the consumer.

- Education for healthful living must begin in the home at the earliest of age; therefore, parent education is a necessity. Consumers must advocate this early education. Early training will reinforce the health education in schools and other efforts in the community for general health education.

- Consumers must insist that coordinated educational efforts be developed to focus on needs in health by consumers and providers, through communications with grass-roots populations.

- Curricula for health education in schools must be a focus for consumers' concerns.

- Consumers should advocate education through mass media, health and social organizations and community workers so that the community will be reached at the grass roots. It is important to use commercially successful advertising techniques through all mass media.

- The consumer must be knowledgeable and aggressive to have adequate input into the system.

- Evaluation of health care is a vital role for the consumer. Evaluation should include use of documents in health care delivery.

- As innovations in health care are planned, consumers as well as providers must help foresee and prevent communication barriers. This implies that consumers are notified of such planning so that they may participate.

- Consumer groups must develop a bill called "Rights for the Consumer in Health Care."

• Consumers must be knowledgeable about health agencies and providers of health care so that input may be developed and ways found to participate, which necessitates *involvement* in one's community. Volunteer participation in the many service agencies, such as hospital guilds, voluntary health agencies and health departments, is a vital pathway for consumer input and education.

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communications

Socioeconomic status, language and culture of both consumers and providers may impede communications, which must involve both the sender and the receiver with equal awareness. Lack of appropriate and formal channels among third party (payer), consumer and provider constitutes a barrier.

Health care may not have the same priority for the consumer as for the provider, which may lead to lack of care. The priority differences need to be recognized and services adjusted to meet needs.

- Consumers should advocate that various "health symbols" of different cultures (medicine man to the Indian, curandero to the Chicano, and witch doctor to the Black) be considered as members of the health care team.

- The third-party payer (the Blues, federal agencies and insurance carriers) should be challenged to open the lines of communication to make the health care system function more effectively.

- Supplemental services must be implemented to meet consumer needs where priorities are divergent.

For the provider to be effective in health care, he must be aware of and receptive and responsive to consumers' needs and expectations. To develop this component in the provider group, providers must participate in the community activities related to health care–outside of their professional practice.

- Consumers should encourage communication through indigenous workers and families by the provider. This will enhance the service–particularly in breaking down the barriers of culture and language.

- Consumers should insist that providers make opportunities for meaningful consumer participation. Group providers should lead in the use of patient advocates (ombudsmen) as a member of the service.

- Consumers should insist that providers ensure adequate communication among health professionals to guarantee quality of care.

There should be pre-planning by planners, providers, consumers and third-party payers to prepare the general public for the innovative practices in the delivery of health care that are being developed for the future.

- Consumers and providers must establish a line of communication with legislators to ensure input and proper planning that will prevent future barriers in health care.

- Consumers, together with providers, should be aware of any proposed legislation (national and state). The legislation should be perused, discussed and researched at the local level by concerned citizens and then pursued via testimony pro or con before legislative committees. In this way, consumers and providers can make certain that emphatic, positive stands are made known to lawmakers.

Communication and understanding is lacking between doctors and other health care workers and patients, particularly where cultural differences exist. Providers and consumers have a dual responsibility to understand each other's roles and responsibilities. The average consumer views the provider as the "indisputable scientist," and the provider often views his professional knowledge as unquestionable and he appears authoritarian. The medical profession has become mechanical, business-oriented, remote and impersonal.

- Consumers should demand that medical terminology be translated into and explained in their own language.

- Consumers should insist that health professional and para-professional education be more conducive to human and cultural awareness.

- Consumers should demand that more multilingual personnel from local populations be employed by doctors and health care organizations.

- Consumers should encourage the development of cross-cultural understanding of concepts of illness and methods of communicating them.

- Consumers and providers should be more aware of the distinction between the medical profession and the total health care system.

- Consumers should advocate the development of a coordinated health care system, which does not exist, as differentiated from the existing "medical system."

- Consumers should develop an avenue for input into the educational and professional development of providers.

- Consumers should encourage the development of a health care system that would allow the socioeconomically deprived to become providers and receivers in sufficient numbers.

- Professionals from the dominant culture need to be educated so that professionals from local cultures do not have to adopt the dominant culture's value system.

• Consumers should advocate that experience and knowledge, in lieu of formal education, be recognized more than it is. This should reduce one barrier to effective use of manpower in the health care system.

• Consumers should encourage input from communities and from the humanities into medical education curricula.

• Consumers should advocate the development of easier access for consumers to contribute to health planning and development activities, as well as to the consumer's own medical care.

cultural patterns

There is inadequate health education for consumers, particularly for the nation's various cultures and ethnic minorities. Health education has previously been aimed at professionals by virtue of the language and technical terms used in such education. Existing public school health education is inadequate for children and does not reach adults. In addition, health education materials available do not consider cultural health patterns. The American value system is deficient in that it places a low priority on health. This tendency especially works against the health interests of minorities.

- Consumers must advocate the development of social mechanisms to make the physician's responsibility to educate the patient become an integral part of patient care. The consumer must have an active role in ensuring that this mechanism is implemented.

- Consumers and providers must develop mechanisms to recognize and validate health information systems that do exist in communities.

- Consumers should advocate that an increased priority be assigned to health education activities in schools and other public organizations.

- Consumers should encourage research to document and recognize health needs specific to various cultural groups. This information would aid in the development of more relevant health education programs.

- Consumers should encourage research and documentation of the uses of folk medicine. An educational program for health practitioners and consumers regarding folk medicine should be developed.

- Consumers should encourage the development of a mechanism through which information can be fed to the community regarding relevant health issues; i.e., legislation, health maintenance organizations, and others.

cultural patterns

Consumers must encourage interaction between cultural peer groups and health care providers. Health providers often do not participate in community programs. The health care system imposes unrealistic time and value restraints on providers. Many cultural groups who get health training do not practice in their communities largely because of financial reasons. Both consumers and providers often suffer from a lack of interest in each other, and professional groups' structures often exclude consumer input. There is no defined mechanism by which consumers can enter into effective interaction activities.

- Many consumers feel that professionals view themselves as superior to consumers, thus preventing effective interaction.

- Consumers should also recognize that they themselves often suffer from an inferiority complex when dealing with providers.

- Consumers should be involved in selection of students being trained for health careers.

- Consumers should encourage the involvement of both health professionals and health care students in consumer activities.

- Consumers should take an active part in strengthening health planning councils.

- Consumers should be part of a national pressure group that includes providers.

- More opportunities for professionals from the local culture to practice in their own communities should be provided.

- Consumers should have positions on peer review boards.

- Cultural groups that have been through the established educational system also need re-sensitization in human awareness and cultural values.

- That there is no state office or other mechanism to compile patient complaints and act as a medical consumer-provider liaison should be corrected.

- There is a definite need to hire patient advocates on staffs of hospitals and clinics.

- The medical value system is so different from the consumer's usual value system that it is difficult for him to relate to it.

- There is a need for doctors and other professionals to redefine their role to include participation in the community as well as treatment of illness.

cost

The problem of health care costs must always be considered within a socio-environmental framework. Such factors as employment, housing, education, pollution, etc. have an overriding effect on consumer judgment and demand for health care services. Consumers can play specific roles, direct and indirect, in the reallocation, if not the reduction, of health care costs.

- Consumers must be made aware of the cost of duplication of facilities and services.

- Consumers must be given knowledge of the cost effects of medical practice acts and professional restrictions.

- Consumers must urge physicians and pharmacists to find ways of reducing costs through the prescription of appropriate quality drug substitutions.

- Consumers must learn to differentiate between medical and social needs; recognize the high fees may not mean quality care, and understand the quality and cost effects of over-demand and under-demand.

- Consumers must realize the cost of "defensive medicine" and move against the abuse of malpractice suits.

- Consumers must receive more information as to the cost and value of ancillary services.

- Consumers must be made aware of their prerogatives in demanding different methods of treatment and payment (such as health maintenance organizations and health insurance).

- Consumers must encourage continuing education and recognize that this is a basic cost of quality care.

- Consumers must be made aware of different levels of care, such as hospitals, ECF's, nursing homes, home health care, etc.

- Consumers must be made aware of paramedical capabilities. Acceptance will lower demand for more costly physician services.

• Consumers must understand the cost of specialization and encourage physicians towards a more rational use of specialists.

• Consumers must recognize the cost of growing unionization among all categories of health workers.

• Consumers must understand their role in influencing case management–the process by which a patient moves through the health care system.

• Consumers must participate in utilization review and control mechanisms.

• Further explanation of alternative health care systems is necessary and desirable.

• Continuing emphasis must be placed on preventive services and ambulatory care.

• Consumers must be made more aware of all the factors that affect the cost of health care.

• Consumers need to recognize the cost effects in achieving the values of more available, accessible and acceptable health services.

• Consumers must expand their participation in all phases of planning for health care delivery.

• Consumers must be educated to take care of health problems themselves (self-help) where appropriate. This education must be provided at all levels, including schools (colleges) of education.

• Consumers must demand reasonable medical information on which to base a decision regarding their own health care, including the cost of that health care.

(Caffie Greene, a task force participant from California, filed a minority report regarding the cost workgroup statements. She said she neither accepted nor understood the statements.)

Appendix I

Invitation Package

Letter of Invitation
(Example)

Dear _____:

You are cordially invited to become part of an ad hoc task force May 9-11 in Albuquerque, New Mexico, that will produce a document outlining the consumer's role in assuring quality health care. Attendance will be by invitation only.

Sponsored by Regional Medical Programs in New Mexico, Mountain States and California, this task force will develop a document that will be consulted, refined, and examined for years to come.

As you are probably aware, all past conferences dealing with quality of care have focused almost exclusively on the process of health care delivery; and, they have stressed the need for peer review and other kinds of professional monitoring of quality.

The Albuquerque invitational task force, as you can see from the enclosures, will ask, and then answer, a number of specific questions about how the consumer can influence five basic elements of health care (access, process, compliance, continuity, and outcome). Questions will be asked such as, "How can I enter the health care system?" "How can I affect the quality of health care while I am receiving it?" "Can I understand the treatment (or health care) instructions?" A number of questions will be posed, too, about how communications, cultural patterns and cost can help or hinder quality health care.

We expect this task force to be on the leading edge of the trend toward the consumer's participation in his own health care, and his justifiable concern about its quality. The document produced by this task force will be published and distributed nationally to mobilize the country's thinkers, planners and opinion-makers to address questions of health care quality assurance from the viewpoint of the consumer.

As you can see from the agenda, the Albuquerque meeting is oriented toward significant *out-put* -in contrast to earlier conferences concerned primarily with in-put. Only a few speakers will be heard; most time and effort will be spent in reaching the enclosed objectives. *You* have been chosen for this invitation because of your knowledge and your reputation for hard work and production.

Note that we have titled the meeting "A CHARRETTE: The Role of the Consumer in the Quality of Health Care." "Charrette" is a French term meaning hand-cart, and now being defined as a *working* meeting. French history points out that when the French government had a construction job requiring the effort of more than one architect, outstanding specialists were gathered from throughout the country. These architects would carry their equipment in charrettes, and thus were prepared for intense, productive activity.

Fewer than 100 persons have been invited to participate in this task force. They represent government health officials (national, state and local), comprehensive health planning agencies, medical societies, Regional Medical Programs, voluntary health agencies, allied health workers, community clinics, medical schools, political leaders, national union leaders, and others. The majority of invitees are from Western states.

Because of the significance of this task force, and because of the careful screening of potential attendees, *this invitation is not transferrable.* (If you cannot participate, you may contact us for consideration of a replacement recommended by you.)

Your input is needed. Please return the enclosed registration form indicating you will attend. This form must arrive in our offices before May 1. You should make your own reservations at Albuquerque's Holiday Inn East by returning the enclosed postcard. A $15.00 registration fee will cover your luncheon May 10, with the rest going toward conference expenses and publication costs. Unfortunately, you must pay your own transportation and lodging expenses.

Free transportation from Albuquerque's International Airport to the Holiday Inn East is available. Call the Holiday Inn East from the airport (near the baggage area) when you arrive.

Your attendance at this meeting will guarantee that your viewpoint is recognized and noted in the first document ever produced that addresses the consumer's role in quality assurance of health care. This publication will be nationally distributed and may become the consumer's quality care constitution.

We look forward to seeing you in Albuquerque May 9.

Sincerely,

James R. Gay, M.D.
Coordinator

Enclosures: (6)

A CHARRETTE: The Role of the Consumer
In the Quality of Health Care

May 9, 10, 11
Holiday Inn East
12901 Central Avenue N.E.
Albuquerque, New Mexico

Sponsored by Regional
Medical Programs in New
Mexico, Mountain States
and California

A WORKING INVITATIONAL TASK FORCE
TO PRODUCE A DOCUMENT OUTLINING
THE CONSUMER'S ROLE IN ASSURING QUALITY HEALTH CARE

Wednesday
May 9, 1973

4:30 p.m.- 7:30 p.m.	REGISTRATION (Holiday Inn East, Lobby)
7:30 p.m.- 7:45 p.m.	WELCOME James R. Gay, M.D. Coordinator, New Mexico Regional Medical Program (El Matador Room)
7:45 p.m.- 8:15 p.m.	KEYNOTE ADDRESS Walter B. Clancy, J.C.D. Associate Professor of Social Planning and Community Organization University of Arkansas Graduate School of Social Work Consultant to HMO Service, HSMHA (El Matador Room)
8:15 p.m.- 8:30 p.m.	CHARGE TO TASK FORCE C. E. Smith, Ph.D. Director, Operational Programs and Evaluation Mountain States Regional Medical Program (El Matador Room)
8:30 p.m.- 9:00 p.m.	WORKSHOP LEADERS' CAUCUS Charles White, Ph.D. Associate Coordinator, California Committee on Regional Medical Programs (El Matador Room)

8:30 p.m.-10:00 p.m.	RECEPTION (Holiday Inn East, Bar Area)
10:00 p.m.	RECESS

Thursday
May 10, 1973

8:30 a.m.- 8:45 a.m.	ENERGIZING SESSION James R. Gay, M.D. Coordinator New Mexico Regional Medical Program (El Matador Room)
8:45 a.m.- 9:00 a.m.	WORKSHOP ASSIGNMENTS Charles White, Ph.D. Associate Coordinator, California Committee on Regional Medical Programs (El Matador Room)
9:00 a.m.-10:30 a.m.	WORKSHOPS *Access:* Room 100 *Process:* Room 102 *Compliance:* Room 104 *Continuity:* Room 106 *Outcome:* Room 108 *Communications:* Room 110 *Cultural Patterns:* Room 112 *Cost:* Room 118
10:30 a.m.-10:45 a.m.	BREAK/REFRESHMENTS (poolside, weather permitting; otherwise in lobby)
10:45 a.m.-12:00 noon	WORKSHOPS Same as above
12:15 p.m.- 1:30 p.m.	LUNCHEON Steak Sandwiches (La Fiesta Room) Speaker: Ernest A. Mares Cultural Laboratory New Mexico Regional Medical Program
1:30 p.m.- 3:00 p.m.	WORKSHOPS Same as above
3:00 p.m.	REFRESHMENTS (Optional at Group Leader's Discretion; Available until 3:30) (poolside, weather permitting; otherwise in lobby)

3:00 p.m.- 5:00 p.m.	WORKSHOPS Same as above
5:00 p.m.- 7:30 p.m.	RECESS (Workshop Leaders will hand in materials to registration desk at 5 p.m. to be typed and reproduced)
7:30 p.m.- 8:30 p.m.	RECEPTION (Holiday Inn East, Bar Area)
8:30 p.m.	RECESS

Friday
May 11, 1973

8:30 a.m.-10:30 a.m.	WORKSHOP REPORTS Workshop Recorders (El Matador Room)
10:30 a.m.-10:45 a.m.	BREAK/REFRESHMENTS (El Matador Room)
10:45 a.m.-11:30 a.m.	DISCUSSION Comments on Workshops; General Discussion All Participants (El Matador Room)
11:30 a.m.-12:00 noon	TASK FORCE WRAP-UP Dr. James R. Gay Coordinator, New Mexico Regional Medical Program (El Matador Room) Task Force Evaluation Sheets completed and collected
12:00 noon	ADJOURN

A CHARRETTE: The Role of the Consumer
In the Quality of Health Care

A WORKING INVITATIONAL TASK FORCE
TO PRODUCE A DOCUMENT OUTLINING
THE CONSUMER'S ROLE IN ASSURING QUALITY HEALTH CARE

GOAL:
To produce a detailed document that defines the role of the consumer in the improvement of the quality of his own health care.

ASSUMPTIONS:
1) Five basic elements of health care are: Access, Process, Compliance, Continuity and Outcome (See questions relating to health care elements.)
2) Communications, cultural patterns and cost can all either help or hinder quality health care. (See questions relating to health care elements.)

OBJECTIVES:
1) To produce at least five statements that define the major roles consumers can play in each of five basic elements of health care: Access, Process, Compliance, Continuity and Outcome. (See questions relating to health care elements.)

Each statement will consist of two to three sentences. Each statement will be followed by a narrative explanation of the meaning of the statement, with a description of the practical applications.

2) To produce at least five statements that define the major roles consumers can play to improve health care through an understanding of cultural patterns, better communications and appropriate health care costs. (See questions relating to health care elements.)

Each statement will consist of two to three sentences. Each statement will be followed by a narrative explanation of the meaning of the statement, with a description of the practical applications.

FORMAT:

Eight workgroups will be formed, each of which will address *one* of the following: Access, Process, Compliance, Continuity, Outcome, Communications, Cultural Patterns and Cost. (See agenda.)

The members of each workgroup will develop at least five statements regarding their topic. Each statement will consist of two to three sentences. Each statement will be followed by a narrative explanation of the meaning of the statement, with a description of the practical applications.

Each workgroup will have a "workshop leader," who will moderate the discussion and ensure that the objective is met. Each workshop leader will appoint a "recorder," who will write out the statements, the narratives and the descriptions, and will present a summary to the entire task force May 11. (See agenda.)

Each workshop leader will be responsible for turning in his workgroup's material at 5 p.m. May 10. (See agenda.)

The entire task force will have an opportunity to discuss each workgroup's report during a general session May 11. (See agenda.)

(SUGGESTED)
QUESTIONS RELATING TO HEALTH CARE
ELEMENTS

WORKSHOP TOPICS

ACCESS:
"What can I do, and what should health care workers do, to be sure that I know how to enter the health care system?"

PROCESS:
"How can I affect the quality of health care while I am receiving it?"

COMPLIANCE:
"Can I understand treatment (or health care) instructions?" "What can I do to assure that I understand and will comply with treatment (or health care) instructions?"

CONTINUITY:
"What can I do, and what should health care workers do, to be sure that my health care is continued until no longer necessary?"

OUTCOME:
"What can I do, and what should health care workers do, to be sure the results of my health care are satisfactory?"

CULTURAL PATTERNS:
"What can I do, and what should health care workers do, to assure that I am treated as an individual?" "How can my cultural make-up affect the quality of care, and what should I do and what should health care workers do to break down cultural barriers to quality health care?"

COMMUNICATIONS:
"What can I do, and what should health care workers do, to break down communication barriers to quality health care?"

COST:
"Can I afford quality health care?" "What can I do, and what can health care workers do, to assure that the kind of health care I receive is appropriate in light of my ability to pay?" "What can I do to affect the cost of health care?"

A CHARRETTE: The Role of the Consumer
in the Quality of Health Care

A WORKING INVITATIONAL TASK FORCE
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THE CONSUMER'S ROLE IN ASSURING QUALITY HEALTH CARE

SUGGESTED WORKSHOP PROCESS

Steps

1) Each workgroup member should be asked if he understands the suggested topic question. Does he agree that this question effectively defines the workshop topic? (For example: the question for the workshop on Access is: "What can I do, and what should health care workers do, to be sure that I know how to enter the health care system?") If the participants do not agree, they should be given a brief opportunity to refine the question.

2) Each workgroup member should be asked to identify and write down, on his own, five needs or problems related to the suggested topic question. Then, each workgroup member should choose three of the five needs or problems he has just listed to be recorded on easels and notes.

   All the needs or problems should then be listed (and lettered–A, B, C, etc.) so that each is visible to each workgroup member. Blank space should be left after each need for further refinement (see next step).

3) The group as a whole should then BRIEFLY define what each need or problem means. (Two to three minutes on each need or problem.)

4) The final list of individual needs and problems should then be placed in order of priority for discussion:

   Each workgroup member should, on his own, determine the priority he would like to use (i.e., B-1, D-2, A-3, J-4, etc.). He then gives his sheet to the recorder. The recorder then adds the numbers for all A's, B's, C's, etc. The lettered need or problem with the lowest number total then becomes the first to be discussed. (The remaining needs or problems are placed in descending order, based on the number total of each need or problem.)

5) The group as a whole, for the first need or problem, then:
   a) Discusses why this need or problem exists.
   b) Determines the barriers to the possible roles of consumers in meeting this need or helping to solve this problem.
   c) Discusses some options that may help to decrease the possible barriers the group has just listed.
   d) Lists realistic roles the consumer can play in meeting this need or solving this problem.

*6) The group as a whole then drafts a statement (to reach the objective) consisting of two or three sentences that define the major role consumers can play in meeting this need or helping to solve this problem. (The need or problem should, of course, be contained in the statement.)

*7) The group as a whole then agrees on the wording of the narrative explanation of the meaning of the statement the group has just drafted, and also agrees on the wording of the description of the practical applications (and implications) of the stated consumer role.

8) The group as a whole then repeats the process described in steps 5, 6 and 7 for each of the remaining needs or problems identified in step 2. (The order of discussion was determined in step 4.)

THEREFORE, at the conclusion of the workgroup session, for each need or problem:

A) A statement, consisting of two or three sentences, has been drafted that defines the major role consumers can play in meeting the need or helping to solve the problem.

B) Each statement is followed by a narrative explanation of the meaning of the statement, with a description of the practical applications.

---

*Step 5 (A through D) should have already accomplished the substance of steps 6 and 7. All that should be needed in steps 6 and 7 is agreement on specific wording.

SUGGESTED TIME SCHEDULE FOR EACH WORKSHOP

STEP	TIME ALLOTED	TIME OF DAY
1	15 minutes	9:00- 9:15 a.m.
2	25 minutes	9:15- 9:40 a.m.
3	50 minutes	9:40-10:30 a.m.
MORNING BREAK		
4	15 minutes	10:45-11:00 a.m.
5	30 minutes	11:00-11:30 a.m.
6	15 minutes	11:30-11:45 a.m.
7	15 minutes	11:45-12:00 noon
LUNCH		
8	3½ hours*	1:30- 5:00 p.m.

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*Presumably, discussing the first need or problem and drafting the statement about the consumer's role will require more time than discussion and statement-writing of succeeding needs and problems. Being familiar with the process, learned in the morning session, should speed the afternoon's products.

Regardless, it seems that our early objective of each workgroup's drafting at least 10 statements, with descriptions, is unreasonable. We have adjusted our objective so that each workgroup is expected to draft at least five statements.

Appendix II

Participants

Access Workgroup

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Appendix III

Welcome Address

Welcome

James R. Gay, M.D.
Coordinator, New Mexico Regional Medical Program

Welcome to Albuquerque, to New Mexico, and to this conference on the role of the consumer in the quality of health care.

The sponsors of this conference are the Regional Medical Programs of California, Mountain States and New Mexico.

The principal representatives of those regional medical programs here today are Charles White, Ph.D., California; C. Edward Smith, Ph.D., Mountain States and James R. Gay, M.D., New Mexico.

The logistical support for this conference is being provided by the program staff of the New Mexico Regional Medical Program (NMRMP). The chief organizer is Jim Pulver, public affairs officer.

If you have suggestions regarding the content of the conference as we go along, you might direct them to Charles White, Ed Smith or myself. We will do our best to accommodate your suggestions.

However, if you have suggestions regarding the arrangements of the conference or any personal requests that we can take care of, you can direct them to Jim Pulver or any member of the NMRMP staff.

In general, people with black badges are the people to whom you may make suggestions.

So much has happened since we began planning, I'm having a difficult time really deciding how this conference all came about. I know that many people, both consumers and providers, have been concerned about quality health care for a long time. I know too that there has been a recent resurgence of interest in the maintenance of high quality health care. All of us are aware that there was interest expressed in the "New Mission Statement" for regional medical programs issued in June 1971. I am sure that public concern has also highlighted this subject in the debate over the professional standard review organizations (PSRO), created to serve Medicare and Medicaid programs.

We also know that the quality of health care is a recurring theme in discussions about national health insurance and in proceedings concerned with health professional organizations.

Among our staff at the New Mexico Regional Medical Program we have been talking, in a planning and programmatic way, about the quality of health care for about a year and one-half. I think the most comprehensive national event to occur in this area was the quality assurance meeting sponsored by the Regional Medical Programs Service. It was held in St. Louis January 23-24, 1973, and we were pleased to receive copies of the proceedings of this conference in the mail just yesterday so that you could have a copy for your library. We believe this was a milestone conference. However, I must admit that there again—as in many previous conferences—the emphasis has always been from the standpoint of the provider.

We've been speculating on the role of the consumer in health care and its quality. This conference is a result of our speculation.

You have been invited here to begin the process of balancing the roles of the provider and consumer in health care for the future. In particular, their roles in assuring the quality of health care.

We call this meeting a "charrette" because it is a working conference. This is not the kind of conference where you merely sit and listen. We are doing a little bit of keynoting

tonight, but tomorrow and the day after we will all be contributing to the conference. Each of you is a speaker and each of you is a member of the audience.

The format of the "charrette" has been very carefully researched. It is designed to assist you in writing the proceedings of this conference as it continues. As a result it shouldn't take us very long to get this material back to you and to others who may be interested in it.

You have not seen or heard public announcements about this conference. That's because it was planned to be what we call a "low-profile" event. The reason for this low visibility is to avoid any extra anxiety on the part of the PSRO and new health care foundations.

These provider groups–concerned with the quality assurance of health care–are still struggling with their new-found roles and we do not want to indicate to them that there is any competition between what we are doing here and what they are doing.

As a matter of fact, it is our thinking that this conference will complement those new efforts, and not in any way conflict with them.

We anticipate that the consumer will have a strong role in quality assurance of health care.

In a sense we are explorers of the future in these deliberations.

I have one major suggestion to make concerning our proceedings. I think we should approach our task using the "Zero Base Budge," that the legislature usually wants us to follow quite exactly.

Using the "zero base budget" an administrator starts with no funds–zero funds. Then each budget item is considered. For example, every activity is scrutinized for effectiveness and every dollar is justified before it is actually entered in the budget.

As we look at health care and its quality assurance during the next two days, we might use a zero base participation approach.

Starting from a base of absolutely no role for the consumer in health care, we can discuss a variety of possible roles for the future.

As each of these new roles is scrutinized and justified, we can put it into a program of quality assurance in which it should have a part.

We call this process "zero base participation" in quality assurance.

Appendix IV

Keynote Address

Keynote Address

Walter B. Clancy, J.C.D.
Associate Professor of Social Planning
and Community Organization
University of Arkansas Graduate School of Social Work
(Consultant to Health Maintenance Organizations Service,
Health Services and Mental Health Administration,
U.S. Department of Health, Education and Welfare)

Ladies and Gentlemen, I am deeply honored at the privilege of addressing such a distinguished gathering as this. The subject of our conference truly excites me; the environment is excellent; the charge before us is specific; the company is beyond compare. Let us begin.

Defining "the role of the consumer in the quality of health care" sets before us an awesome task. I see my function here tonight as presenting some ideas that mark a beginning in stimulating our thinking on this all-important subject concerning the future of health care. I want to begin by talking about the "activated patient."

I think it was Dr. Vernon Wilson, late of the Federal Health Establishment, who encouraged the use of this term—early in the Nixon administration. We can see what Dr. Wilson had in mind. This sleeping giant of a patient must bestir himself and become involved in issues concerning his own health, if he is truly interested in the future quality of health care. The use of the adjective "activated" was a sort of mild first step towards the use of a term that stuck in the throats of most health providers: "consumer." The implication of this term I want to examine in a moment.

The use of the term "activated patient" also contains such contradictions that it might serve to bring out the ambivalence with which many persons approach a discussion of the consumer and his involvement in the health care system. These mixed feelings are especially found in persons who are employed in or around the health facility. They are at once actors and movers within the system and recipients, along with their loved ones, of health care. They are at once beholden to the system and expect from it the rewards their services deserve. They admire the strengths of our delivery system but at the same time see its myopia and shortcomings. They play the games the system demands while all the time wanting to spend this energy addressing the problems of the urgent immediate future. These feelings need attention at the outset of any conference such as this. We could waste a lot of valuable time qualifying our remarks of the next few days. For purposes of our work here, let us all assume the role of the "activated patient" who sees himself as more than one who passively receives the services of the system, but is actively concerned with the where, why, what and how of these services as they impact on the quality of health care. In other words let us act as "concerned consumers."

According to many authorities this is the stimulus for change that exists at the present time in the health care delivery system. The patient-client is more and more defining his role as consumer. Reeder (1972) speaks of the implications for change growing out of this redefinition of the provider-client relationship. These changes he identifies as:

1) The orientation of medical care away from treatment to prevention with the consequent adjustment in the way the professional interacts with the consumer of his services.
2) The provision of medical care within organizational structures as distinct from solo practice with the consequent lessening of personal interaction between the professional and his client.

3) The strength of consumerism as a social movement.

It's interesting that Reeder applies labeling theory of deviance in making his analysis. The process of social change evidenced by this evolution in relationships from patient-practitioner to consumer-provider, he says, is indicative of structural changes developing in the health care system. It seems to me that one of our tasks at this important conference is to anticipate these developments and search them out to see how they impact on the quality of health care. Let us take the notion of prevention as opposed to treatment as an emphasis in health care. The implications are tremendous. Perhaps this is the reason we have not been able to do more than give lip service to this approach to health. And again, maybe this is not the legitimate concern of the provider but the province of the consumer of health care.

This brings to our attention the functional distinction between health and medicine, between health care and medical care. In conceptualizing this distinction Howard (1971) sees medicine as a private affair relying on a one-to-one physician-patient relationship supported by hospital facilities. Health he views as the broader participational concern that cannot be separated from environmental, social and economic influences. He states that–

> Clearly, the required strategy for health care is outside the realm of medicine. While better medical treatment depends on professionalism, the health agenda is in the realm of public affairs. This means for improvement is not professionalism but politics.

I'm not sure I agree with all the ramifications of that statement as regards the quality of health care, but the usefulness of this distinction here is obvious. The practice of medicine in the past has been such an individualistic and entrepreneurial exercise that any attempt of the patient-consumer to become involved in any intimate way has been viewed as a breach of professionalism and an encroachment upon the practice of medicine. During the latter half of the 1960's the OEO Neighborhood Health Centers were the battleground for this kind of controversy. Consumer groups demanded peer-like privileges. The effort was resisted and accommodations developed. But two lessons at least can be drawn from these experiences. Maybe the low-income consumer was right in asking a voice in what so intimately affected him. His lack of sophistication in asking should not cloud our view of the basic issues involved. As a matter of fact, most so-called attempts to "practice medicine" by OEO-Model Cities consumer groups were usually attempts to make a needlessly obstruent system render an acceptable level of health care.

We have demythologized everything else. Perhaps it's time we applied this process to medicine. The second lesson is that middle-class America learned the lesson of protest well. No longer will any significant group in this country trust a service-delivery system in our society to automatically insure its best interest. The health care system, like other systems and most people, operates better when it is watched.

Here let me return briefly to the distinction made above between health and medicine. This dichotomy seems to suggest that the consumers' interest lies in health and the providers' interest is in medicine and never the two shall meet. I think while this is generally true, in very real ways the distinction breaks down. The physician's interest in health is obvious. Not so obvious is the consumer's involvement in medicine. Here is one of the thorny issues that this conference is charged to deal with. The presently used mechanism to deal with quality of medical care is peer review. Is this satisfactory from a consumer point of view? I think not. No group in history has ever so successfully controlled its own self-interest as to regulate itself completely from within. The question is not whether the consumer will be involved in assuring quality in medical care, but *how* he will be involved. Many believe that the major barrier to developing more comprehensive national health insurance programs is the lack of a proved model for citizen participation in the quality control of medical practice. We have found ways of regulating other franchised activities in the public domain by citizen-dominated boards. We can find ways of assuring quality medical care, if we put our minds to it.

The problems of quality are not issues of personal or professional competence but

issues of structure and organization. Who influences the health care system? To whom is it responsive? Some have suggested the existence of a "medical-industrial" complex that is more responsive to the drug house and medical supplies than the consumer of service. We won't take time with this issue. Like every exaggeration, it contains a grain of truth. We do know that medicine is not responsive to the normal market mechanisms that once afforded some protection to the consumer. It must be admitted that the general public does not feel any sense of urgency in this matter. Strickland is his *U.S. Health Care: What's Wrong and What's Right* documented the fact that people in general are quite satisfied with the health care system, except for some vague and undifferentiated complaints about the high cost of care. This is deceptive.

Mydal (1970) and others have documented the fact that within our own present level of social organization, the flow of influence is from interest groups to people rather than the other way around. The point here is that the health care system would do well to listen to its well-motivated and friendly critics now rather than face the wrath of an aroused public with the rather irrational results that that often entails.

Kissick and Martin (1972), addressing themselves to "Issues of the Future in Health," state that health care exists in a "no-man's land" as far as accountability is concerned. With a tax bill approaching $20 million a year, they see health care changes in both structure and function within the next ten years.

It is their opinion that:

> The relation of health care delivery system to society is being clarified. Provider dominance of the last quarter century is being challenged by such diverse organizations as labor unions, community boards, and federal, state and local government. The alignment of the third party with the provider is being eroded and some third-party organizations are speaking for the patient.

Allow me another rather lengthy quote from Eliot Friedson (1970) who has devoted most of his scholarly life to the study of professional in the health care field:

> The present system of organizing health care relies too much on the dominance of medical authority in a contest of diffuse responsibility and accountability. Only reorganization of the terms and mechanisms of the system can provide an environment in which the profession can be more honest and its services better. Such a reorganized system consists of an administrative framework that maintains the legitimate prerogative of the professional worker while insisting on the essential obligation to regulate himself in the service of the public. And, not least of all, it establishes the essential right, indeed obligation, of the patient to serve as an active participant of the process of shaping the services that are supposed to exist for his benefit.

Friedson sets our charge at this conference (establishing) ". . . an administrative framework that maintains the legitimate prerogatives of the professional worker, and . . . establishing the essential right . . . of the patient to serve as an active participant in the process. . . ."

Defining the alternate ways of operationalizing the "activated" type of consumer role is our challenge. Let us briefly touch upon each of five workshop topics in this context.

Access to health care is an area where there can be a clearly defined role for the health consumer. This could consist of a shift in priorities and economic incentives away from acute care to preventive care, after the pattern of the HMO. Or it could concern itself with removal of cognitive gates that act as barriers to entry for certain ethnic and economic groups. The access to health services for the elderly poor under Medicare as compared to others in the population supports the belief that lack of financial means is not always synonymous with lack of access. If we fully search this notion it should lead us to some pretty statements about our societal values.

A very forceful report titled *Heal Yourself* by the Citizens' Board of Inquiry into Health Services of all Americans written under the chairmanship of Dr. Lester Breslow says this about the quality of health care and its *process:*

The power of the consumer to control and influence the delivery system must be exercised at every level of the health care system: facility, service system or program, and neighborhood, city, state region or nation. This power should include, but not be limited to making policy, controlling assets (including capital expenditures), facilities, equipment and services. This does not mean that consumers will usurp the doctor's responsibility for meeting his patients' medical needs. On all levels of decision making, clear lines between policy (the consumer's primary business) and professional judgment regarding the individual patient (the physician's primary business) should be established.

Compliance concerns itself with communications. The health professional's involvement is often so intense that he ceases to have the ability to clarify instructions and answer questions. The activated patient can help the physician by explaining that he is not another physician and needs understandable instructions. Compliance, I suggest, can have a larger dimension in terms of environment, sanitation or diet—am I listening to what informed health leaders are telling me? Drug addiction and traffic accidents could be considered here.

Continuity of care demands dialogue and planning for the allocation of scarce community resources. We are beginning to talk about health networks: of hospitals in relation to one another and to ancillary institutions such as nursing homes. Somehow we have to direct our attention away from what benefits a specific health facility or institution and towards what benefits the patient. Left to their own devices, it is perfectly normal for institutions to protect their own interest. This is so expected that it is taken into account in planning for continuity of patient care.

Outcome is what the system is all about. How to measure quality of output is the problem. Well-being is difficult to quantify, but it must be done. Here is where the consumer must find that measure of quality that is at least minimally satisfying, at a cost he can afford, or the system has failed.

It is the activated patient, the involved consumer, who must concern himself with the issue of the quality of health care. It is he who must make available the resources and think through the policy in this vital aspect of our personal and national life. Tonight we gear up to make our contribution. May the products of this working conference be in proportion to our efforts and may our efforts be considerable in this exciting and challenging undertaking.

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Appendix V

Charge to Task Force

Charge to Task Force

C. E. Smith, Ph.D.
Director, Operational Programs
and Evaluation
Mountain States Regional Medical Program

We are here to develop practical ideas, to pool them together into some form of a document, to test them against one another and then record them and distribute them. I think a lot of what we do can fit easily into the framework that Dr. Clancy was talking of -the activated consumer who is concerned about his rights and about how he can ensure himself and the people with whom he most closely relates the best possible quality of health care and at the same time maintain the appropriate professional prerogative that insures the achievement of the best health care he can.

The conference after tonight is composed solely and exclusively of small groups in various combinations of you people here. Our task during those small workgroups is to talk about those aspects of health care that we are best qualified to talk about, the point of view of our own consumer experience–of our own experience with a patient or the people close to us as a patient–and to try to balance those kinds of experiences, move them among one another, test them out, and see what kinds of ideas we can record. These ideas may have some impact on the developing quality assurance mechanisms or quality assurance systems which will undoubtably get established in this area in the next few years or so.

As Dr. Clancy said, what we get out of this conference will be directly in proportion to the amount we are able to put into it. Good luck.

Appendix VI

Energizing Session

Energizing Session

James R. Gay, M.D.
Coordinator, New Mexico Regional Medical Program

"Quality assessment," "quality assurance" and "quality control" are spoken with such emotional emphasis that many persons interpret these terms as new concepts in health care.

The quality of health care is in fact a very old pursuit of health professionals.

There are very few human activities more heavily monitored than health care.

A physician is screened through the educational system in primary and secondary schools, in college and medical school, and in graduate training centers.

Each of the institutions he or she attends is, in turn, scrutinized by an accreditation process. Later, he or she is examined and registered for a state license and for certification as a specialist.

Hospitals must be accredited and they, in turn, monitor the work done on their premises by a physician.

Patients judge the services rendered by their physician and make individual assessments of the quality of their care.

A number of private and public agencies watch health care from a variety of viewpoints –professional deportment, mistakes, detection, professional conformity, cost comparison and other perspectives.

All the health workers working with the physician have their own set of training requirements and of certification procedures.

In addition to all these checks and balances, there is the internal performance control of idealism. Health workers as a group are highly motivated and highly idealistic; and they are endowed with a superior sense of responsibility. These characteristics drive health workers to attend continuing education conferences, to learn new skills, to teach each other, to assist newcomers in their field, to assume increasing responsibilities as their confidence expands, to develop new knowledge through observation, experience and research.

Some are so compulsive about their intellectual excellence that they wear out themselves or their families and friends!

It is a modern miracle that so much dedication is sustained by so many health workers on a voluntary, doing-good-work basis!

And yet, we all know from personal experience that the quality of health care is not always sustained by this vast array of regulatory efforts or by a high level of sensitivity and good intentions. It is interesting to recall that when we have experienced a breakdown in health care quality, it has usually occurred due to discontinuities in delivery of care, rather than to deficiencies in health science.

All of us must continue to rely on educational institutions, on licensing agencies, on professional review activities, on the scrutiny by health care institutions and on professional discipline for most of the technical aspects of health.

It is too late when the bleeding starts to decide if the surgeon knows which vessel to ligate!

On the other hand, an informed and concerned public can make decisions about many things:

–is the service timely?
–is the service appropriate?
–is the service convenient?
–is the service accessible?

–is the service rendered compassionately?
–is every effort made to inform, to explain and to seek understanding?
–is the cost reasonable?
–is the public involved in health matters?
–is prevention or early amelioration as high on the priority list as crisis treatment?

These are questions that consumers can ask and they can assist providers in recognizing needs and designing solutions for problems that are uncovered. I must admit that providers become real spooky when they contemplate untrained people penetrating the privacy of their intellectual line. On the other hand, they very much need the point of view of the recipient of their services, otherwise there is no insurance that their scientific efforts will be successful. They need the input of the consumer also in order to guarantee the emotional rewards that seem to come only from providing personalized human services. There are a vast array of instances when professionals or laymen working together can accomplish much more than they could if they worked separately.

In working together this one and one-half days we need to keep in mind my opening remarks about zero base participation. We need to separate out the items that are clearly the sole responsibility of health professionals, the items that are clearly the responsibility of the public, and the items that should be the joint responsibility of both professionals and public.

It should be possible for us to produce in these next few hours a rational approach to quality assurance that clearly defines the roles of providers and consumers. Now, in contrast to many other conferences which you have all attended it's essential that each of us break the habit of looking at health care through the eyes of the professional. Some of you may consider yourselves pure cultured consumers; but in fact, almost everybody on the list, in one way or another, has some very strong connection with health care and, in most instances, derive some of their income from the health care system. So I ask now for us to put on our consumer glasses and to produce a document fro n a fresh perspective. We can do this. The process will make us "explorers of the future."

There seems to be very little doubt that we are moving into a new level of maturity in our society. One hallmark of maturity is more widespread involvement of people in the institutions they create. This conference should move the process of maturity in health care and its quality assurance a number of steps higher.

Appendix VII

Luncheon Address

Luncheon Address

F. A. Mares
Cultural Laboratory
New Mexico Regional Medical Program

Every overt word has its own ancestry, and I guess if I had to trace the ancestry of what I'm going to talk about here today, it would go back to some of my experiences with the New Mexico Regional Medical Program, and the ancestry would also go back to my experience with an educational process here in New Mexico known as La Academia de La Nueva Raza, or the Academy of the New Humanity, which operates out of Dixon, New Mexico. There is, however, a much more immediate ancestry of my words today, and it goes back precisely 11 days ago, when I had a sudden and dramatic encounter with the Health Care Delivery System.

Eleven days ago, I acquired a pet goat; maybe I shouldn't say goat, because in my neighborhood you're not supposed to have goats as pets, so let's call it a very rare species of American horned, cloven-hoofed dog. That should satisfy all restrictions in my neighborhood. Well, anyway, 11 days ago, I was romping through the fields with my "puppy," enjoying its strange goat-like bark, when all of a sudden the little creature decided to run through a concrete culvert across Route 66, so I lunged at the little animal to prevent it from crossing under the interstate highway. I stopped the goat, all right; however, in the process, my head came into very sudden contact with an old rusty nail that was jutting out from the concrete. It was rather messy.

Well, I had to get to a hospital, an emergency room, to get stitched up, and my wife, who was at the time in a very advanced state of pregnancy, was in our home and I didn't want to frighten her, I very casually walked back and said, "Darling, I have a little problem, I think you may have to take me to the hospital." She almost fainted when she saw me. She drove me to an emergency room in a hospital, 20 miles away, where I was properly put together again. The ending of this story is that less than 12 hours later she went into labor, and so on May 1 we became the parents of a little 6 pound, 4 ounce baby girl.

So the story has a happy ending, but the situation, this emergency, illustrated to me the immense lack of consumer participation in our health delivery system, and I couldn't help but notice while I was glancing through the monograph issued by RMPS, which came out of the St. Louis Conference earlier this year, the article by Leonard S. Rosenfeld, entitled *Standards for Assessing Quality of Care*, because he says some words which, I think, lead very nicely into my main theme today. He says, in case you haven't read it, "While it is humbling for those who devote their lives to the practice of medicine, the more we learn about the impact of social, economic, environmental and behavioral factors on health status, the more we appreciate the fact that medical care is only one of a number of factors, and in many instances a relatively minor factor, in determining the level of morbidity, disability and mortality." So with that I will launch into my little talk which is entitled "Cultural Patterns as the Basis for Entry into New Provider-Consumer Structures Relevant to Quality Assurance of Medical Practice."

As I mentioned earlier, my little emergency made me vividly aware of the lack of community involvement, the lack of any kind of community health network which could respond to the type of crisis situation in which I found myself; the total lack of any community follow-up, and in short, a total lack of consumer involvement structures and mechanisms, and I got to thinking about this question: Why is health care so one-sided, that is to say, why is it so oriented towards the health professional? I think a clue to an answer to that question was given yesterday by Dr. Walter Clancy, when he mentioned that we have demythologized many aspects of our culture, of our civilization,

but we have not demythologized medicine, and I think that if we pursue this theme momentarily, we can see that this might hopefully lead us somewhere.

Medicine is, of course, a special case of science, so if we talk about demythologizing science, I think we can treat the demythologizing of medicine as a special aspect of that case.

You may have noticed that in some of the current sociological literature, the mystique, or the mythology, of science has been increasingly under attack. There was the work of Jacques Ellul, entitled *The Technological Society*, which examined the excesses of industrialism and the grim prospect if we do not develop a more humanistic part of our heritage. There were a couple of recent books by Theodore Roszak, *The Making of a Counter Culture*, and *Where the Wasteland Ends*, which attacked the mythological presumptions underlying modern science: the application of science to totally encompass and define the human experience, to the near total exclusion of all those other factors which are so relevant to the human experience.

There have been some books which have defended the technological *status quo*. One book by a certain Alvin Toffler, entitled *Future Shock*, was a great best seller. Like the other writers of his ilk, Alvin Toffler defends the technological *status quo*. He sees things getting bigger and better every day in every way. Well, historically, every *status quo* has always had its epigones, and it's very seldom that we obtain valuable insights from such people into what the cutting edge of the future is likely to be. Usually you do not find among the champions of the *status quo* the critical insights which are important to developing viable programs for the future.

Looking at mythology briefly, then, I think that mythology is not only pervasive but is also very necessary to the human condition. Those of us who have been working with La Academia de La Nueva Raza have put out a little publication called *El Cuaderno*, which comes out occasionally, *"de vez en cuando,"* as we say, although we put it out quarterly, and we have developed some articles dealing with the problem of mythology and human affairs.

In the case of science, especially medicine in this country, we have, I think, the case of mythology getting out of hand. When one mythology overshadows all others it tends to threaten, if not destroy, the balance of human values. I'm talking, of course, about the perversion of science: the use, or misuse, if you prefer, of science as a myth to overwhelm society. The type of myth which occurs, for example, when you enter the emergency room of a hospital, as I recently did, or the reception room of a doctor's office, and you see everyone dressed in white and wearing all kinds of technical paraphernalia that impresses you. "Hey, wow, this is science. I'm going to get well because I'm going to be subjected to a scientific mode of treatment and it must be good because it's scientific." Seldom do we have the time to reflect that medicine, even "scientific" medicine, has its rites, rituals, and symbols, just as the medical practice of the Indo-Hispano curandero or the Indian medicine man. Well, I think that if scientific mythology, including scientific medicine within that rubric, has become destructive of other human values, as I believe it has, then the question is how to break out of this scientific straitjacket.

I think that Chicano culture is the basis for entry into new provider/consumer structures. For one thing, within the Chicano culture there has been a continuity of prescientific attitudes, beliefs and values. The older Greco-Roman traditions, plus the native Indian traditions which antedate the scientific revolution of the 17th century, live on in full vigor and they form the historic basis of Chicano attitudes towards health. This older tradition tends to stress highly personal, or perhaps we should say personalistic, elements in health care, plus elements which involve magic, wonder, spirituality, a kind of respect for nature, or attitude of awe and reverence towards nature. I would like to illustrate this type of respect for nature which you find. This is in a little ballad which those of us in La Academia published about a year ago, in a book entitled *Entre Verde y Seco* and the ballad is called *"A Debate Between Coffee and Atole,"* and it was first recorded in New

Mexico in 1914 and transcribed in 1971 by Dwight Duran, who is an *asociado* of La Academia de La Nueva Raza, from Las Vegas, New Mexico.

In the debate between Coffee (café) and Atole (atole, by the way, is a kind of cornmeal and it's a very nutritious food), Coffee, coming up out of Brazil, is very, very proud and tries to point out that it is much more important than Corn because dignitaries drink coffee and it's the beverage known all over the world. Coffee comes on very strong; I'll read just a couple of stanzas to give you the flavor of it. Coffee begins by saying:

"¿Cómo te va, amigo Atole,
Cómo has pasado tu tiempo?
Desde mi paiz he venido
A formarte un argumento."

"I've come up from my country to argue with you, Corn."
Corn replies:

"Bien, ¿y a ti como te va?
Y ahora te preguntaré,
Por tu gracia y por tu nombre,
Digame, ¿quién es usted?"

So the debate begins. I'm not going to recount the entire debate, but what finally happens is that Corn, el Atole, wins the debate, because it points out that while coffee exploits the workers in the fields who have to work very hard to produce this luxury item, corn gives nutrition and sustenance to the people who work with it. Finally Coffee, which is on the verge of defeat, says:

"Aunque sea café,
Amigo atole te digo,
No me estés avergonsando.
Quiero que seas mi amigo."

Coffee says,
"Let's be friends, you've won the debate."
And Atole replies:

"Verdad, yo soy el Atole.
Oye, amigo café,
Muchos en el estribo
Los he dejado a pie.
Tambien esto te diré,
Que aunque te empines para el norte,
No dejarás de ser café."

So Corn says to Coffee:

"Even though you come up north, you cross the border, even though you come up from Latin America, you're still coffee and that's all you are, you're still coffee."

And if there is a hidden message, I guess it's that you still retain, you always retain, your cultural ties, particularly if you have been raised in such a dynamic culture as that of the Chicano culture of the southwestern part of the United States.

For all its defects from the scientific point of view, there was, and is, a rich humanistic vein in this attitude toward nature. In this older tradition, the definition of man is a much broader, a much more inclusive, and a much more tolerant definition than the one we find if we accept a mere scientific reductionism of what the human experience is. You would not find, for example, within this older view the excesses of behavioralism. The sadistic experimentation with human beings and animals is unthinkable in this older tradition where man is viewed as an integral link in the chain of nature.

Curiously enough, the Chicano culture, by virtue of adhering to this traditional value system, finds itself in the vanguard of attitudes towards nature represented by some of our most contemporary ecologists. Now, if you've read some of the work of Barry

Commoner, you find this attitude of awe towards nature, viewing man as an essential link of nature, so that Barry Commoner, in many ways, would make a good Chicano.

I might point out, just in passing, that although Theodore Roszak is very impressed by the hippy experience, as a return to nature, without detracting from the merit of that experience, I would like to point out that the Chicano attitude toward nature is not a Johnny-come-lately phenomenon, but rather is deeply rooted in the Indo-Hispano culture going back thousands, if not tens of thousands of years. Within Chicano culture there has been a continuity which stresses the humanistic as opposed to scientific values. These humanistic factors, I would hasten to point out, include scientific values as a part of culture but not as the exclusive definition of culture. In the Hispanic culture, along with peninsular Iberian culture, it is the *artists, writers, and poets, by and large, who are noted,* rather than the scientists.

Within the United States, the position of the Chicano culture is unique, and I think this is very important for health providers. It is a continuous culture. It was never disrupted from its origins as is the case of so many immigrants to this country. We were not immigrants, as I am sure you all know; we were here to greet Columbus and Cortez and all the others who came later. Furthermore, Chicano culture is a very dynamic culture. The Chicano culture of the Southwest has never been cut off from its origins, from its roots, and it has linkages with the vast Indo-Hispano world, and to what we sometimes refer to as the Third World.

The Third World I mention, in this context, is not the third world of political ideologues, but rather the third world which Paulo Freire, the Brazilian educator, refers to as "the third world of the third world," that is, the poor people of this world whose only spokesman is the silence of their suffering. They never rise to the level of being able to verbalize or make known their real needs.

Now what does all this have to do with quality assurance in medical practice? I think it has everything to do with it, especially in the context of the Southwest. Chicano culture offers the health care delivery system a unique opportunity for cultural cooperation. Our culture offers the health care delivery system a very unique learning laboratory experience for bettering human relations, and above all, for broadening the meaning of the human experience of health. La Academia de La Nueva Raza continues moving in the direction which the New Mexico Regional Medical Program was moving towards. The direction of engaging in very exciting approaches to quality assurance. Dialogue, or dialogical encounter, a technique which was pioneered in Brazil by Paulo Freire and also, by the way, pioneered quite independently but in a similar vein here in New Mexico by La Academia, could well be the key to new provider-consumer structures relevant to quality assurance of medical practice. We have the capability, I believe, of creating, of evolving, stream-lined, efficient and effective structures to deal more adequately and precisely with health consumer needs. Chicano culture offers the clue, points the way, towards the new, humanistic bureaucracies which will at least ameliorate, if not altogether end, man's estrangement from man.

Just as an aside, and I'm going to conclude very quickly, all of us, at one time or another in our lives, find ourselves involved in incredible bureaucratic hassles, and I think it is very funny that we try so hard to solve them. Sometimes we succeed and sometimes we fail. My batting average, I must confess, is appallingly poor. Recently I encountered one of these incredible situations. I was invited to give a poetry reading at a state university. I won't mention the state university, but in order to give the reading I had to sign a contract, a standard entertainment contract, and what I had to sign was incredible. I virtually had to agree that my appearance would not trigger the end of the world. I wrote a little poem about it, it's very brief and I think it at least illustrates some of the kinds of concern with bureaucracy that we have in health programs, although this is in a slightly different context. It goes like this:

On Signing An Agreement To Read Poetry
At A State University

Great state university
and all your sage administrators,
you and I do enter into solemn covenant.
I swear I will not bring down on you
labor difficulties, strikes, civil tumults,
wars and epidemics. Neither will I
interrupt or delay transporation service,
nor use salacious, abusive or obscene language,
nor make obscene or offensive
movements or gestures.

If, however, it should happen
that during the reading
the IWW musters its strength
and that One Great Big Union
should call the last General Strike
of all the w[illegible]kers of the world,
and if at th[illegible] same time Yeat's great Beast
slouches to[illegible]ards Bethlehem to be born
amidst floo[illegible]s, earthquakes, tornadoes,
civil wars, and dancing in the streets
then yea, I say unto you as it is written
that Article 3 of the Lecture Agreement and Clause 17
of the Standard Entertainment Contract Rider
shall be fulfilled. You won't owe me a cent
and I won't try to collect.
If we find ourselves, afterwards,
leaving town on the same fast train
I won't look at you
and don't you look at me.

Appendix VIII

Conference Evaluation

Conference Evaluation

The primary evaluation of this conference rested in the desired product – whether a document was produced as described in the objectives and how useful it proves to be in the future. However, participants were also asked for their immediate reactions, and the results are presented here.

Numbers of responses per work group compared to the total number of participants are as follows:

Workgroup	*Total No. of Participants*	*No. of Evaluation Forms Returned*
Access	7	5
Process	6	6
Compliance	6	6
Continuity	8	6
Outcome	7	4
Communications	10	8
Cultural Patterns	8	4
Cost	10	4

Following are all responses to questions on the evaluation form. For each question, total responses to each choice are given by workgroup. Percentages are based on those responding in each workgroup, *not* on total participants. Responses will not always total consistently because for some questions there was no response given.

1. Were the arrangements and information provided about this conference satisfactory?

	Excellent	*Very Good*	*Adequate*	*Inadequate*
Access	3 (60%)	2 (40%)	–	–
Process	2 (33%)	4 (67%)	–	–
Compliance	1 (17%)	2 (33%)	3 (50%)	–
Continuity	4 (67%)	–	2 (33%)	–
Outcome	1 (25%)	3 (75%)	–	–
Communications	5 (63%)	3 (37%)	–	–
Cultural Patterns	2 (50%)	1 (25%)	1 (25%)	–
Cost	2 (50%)	–	2 (50%)	–
TOTAL	20 (46%)	15 (35%)	8 (19%)	–

2. In general, was the time allotted for conference activities:

	Too long?	*About right?*	*Too short?*
Access	–	4 (80%)	1 (20%)
Process	–	4 (67%)	2 (33%)
Compliance	–	2 (33%)	4 (67%)
Continuity	–	3 (50%)	3 (50%)
Outcome	–	2 (50%)	2 (50%)
Communications	–	4 (50%)	3 (37%)
Cultural Patterns	–	4 (100%)	–
Cost	–	2 (50%)	1 (25%)
TOTAL	–	25 (61%)	16 (39%)

3. Was the conference format:

	Too structured?	*About right?*	*Too unstructured?*
Access	–	5 (100%)	–
Process	1 (17%)	5 (83%)	–
Compliance	1 (17%)	5 (83%)	–
Continuity	–	4 (67%)	2 (33%)
Outcome	–	3 (75%)	–
Communications	–	8 (100%)	–
Cultural Patterns	–	4 (100%)	–
Cost	–	4 (100%)	–
TOTAL	2 (5%)	38 (90%)	2 (5%)

4. In view of existing problems in the health care system, the focus of the conference as a whole was:

	Right on target	*Somewhat relevant*	*Only a little relevant*	*Completely off base*
Access	4 (80%)	1 (20%)	–	–
Process	6 (100%)	–	–	–
Compliance	4 (67%)	2 (33%)	–	–
Continuity	2 (33%)	3 (50%)	1 (17%)	–
Outcome	1 (25%)	2 (50%)	–	1 (25%)
Communications	4 (50%)	3 (37%)	–	–
Cultural Patterns	3 (75%)	1 (25%)	–	–
Cost	1 (25%)	2 (50%)	1 (25%)	–
TOTAL	25 (60%)	14 (33%)	2 (5%)	1 (2%)

5 In regard to potential use in alleviating problems, the results of this conference as a whole are:

	Extremely practical, should prove to be well-used guidelines	*Somewhat practical, may be of some use*	*Good theoretical ideas, not of much practical use*	*Mostly philosophical, not at all practical*
Access	3 (60%)	2 (40%)	–	–
Process	2 (33%)	3 (50%)	–	–
Compliance	3 (50%)	3 (50%)	–	–
Continuity	1 (16 2/3%)	3 (50%)	1 (16 2/3%)	1 (16 2/3%)
Outcome	1 (25%)	2 (50%)	–	1 (25%)
Communications	4 (50%)	3 (37%)	–	–
Cultural Patterns	1 (25%)	3 (75%)	–	–
Cost	–	2 (50%)	1 (25%)	1 (25%)
TOTAL	15 (37%)	21 (51%)	2 (5%)	3 (7%)

6. To what extent did the conference as a whole meet your expectations?

	It didn't	*Sort of*	*Adequately*	*Better than I had hoped*
Access	–	–	2 (40%)	3 (60%)
Process	–	–	5 (83%)	1 (17%)
Compliance	1 (17%)	2 (33%)	1 (17%)	2 (33%)
Continuity	–	2 (33 1/3%)	2 (33 1/3%)	2 (33 1/3%)
Outcome	1 (25%)	1 (25%)	2 (50%)	–
Communications	–	1 (13%)	3 (37%)	3 (37%)
Cultural Patterns	–	–	1 (25%)	3 (75%)
Cost	–	1 (25%)	1 (25%)	1 (25%)
TOTAL	2 (5%)	7 (17%)	17 (41%)	15 (37%)

Workshop Evaluation

1. How well do you feel your group worked together?

	It was dominated by a few people	*Everyone participated fairly well*	*Only a few people did not participate*
Access	–	5 (100%)	–
Process	–	6 (100%)	–
Compliance	–	6 (100%)	–
Continuity	–	6 (100%)	–
Outcome	1 (25%)	3 (75%)	–
Communications	–	7 (87%)	1 (13%)
Cultural Patterns	–	4 (100%)	–
Cost	–	4 (100%)	–
TOTAL	1 (2%)	41 (96%)	1 (2%)

2. To what extent did your group reach consensus on your "statements"?

	No consensus, results were compromise	*Some consensus, some disagreement*	*A good deal of consensus, a little disagreement*	*Nearly complete consensus*
Access	–	1 (20%)	2 (40%)	2 (40%)
Process	–	–	2 (33%)	4 (67%)
Compliance	–	1 (17%)	2 (33%)	3 (50%)
Continuity	–	(3 50%)	2 (33%)	1 (17%)
Outcome	–	2 (50%)	1 (25%)	1 (25%)
Communications	–	–	2 (25%)	6 (75%)
Cultural Patterns	–	1 (25%)	1 (25%)	2 (50%)
Cost	–	1 (25%)	1 (25%)	2 (50%)
TOTAL	–	9 (21%)	13 (30%)	21 (49%)

3. In view of existing problems, do you feel that the focus of discussion in your workshop was:

	Right on target	*Somewhat relevant*	*Only a little relevant*	*Completely off base*
Access	5 (100%)	–	–	–
Process	4 (67%)	2 (33%)	–	–
Compliance	4 (67%)	2 (33%)	–	–
Continuity	1 (17%)	5 (83%)	–	–
Outcome	2 (50%)	1 (25%)	–	1 (25%)
Communications	8 (100%)	–	–	–
Cultural Patterns	4 (100%)	–	–	–
Cost	3 (75%)	1 (25%)	–	–
TOTAL	31 (72%)	11 (26%)	–	1 (2%)

4. In regard to potential use in alleviating problems, the results of your workshop are:

	Extremely practical, should prove to be well-used guidelines	*Somewhat practical, may be of some use*	*Good theoretical ideas, not of much practical use*	*Mostly philosophical, not at all practical*
Access	3 (60%)	2 (40%)	–	–
Process	3 (50%)	3 (50%)	–	–
Compliance	3 (50%)	2 (33%)	1 (17%)	–
Continuity	1 (17%)	5 (83%)	–	–
Outcome	1 (25%)	2 (50%)	–	1 (25%)
Communications	6 (75%)	2 (25%)	–	–
Cultural Patterns	1 (25%)	3 (75%)	–	–
Cost	1 (25%)	2 (50%)	–	1 (25%)
TOTAL	19 (44%)	21 (49%)	1 (2%)	2 (5%)

5. To what extent did your workshop meet your expectations?

	It didn't	*Sort of*	*Adequately*	*Better than I had hoped*
Access	–	–	2 (40%)	3 (60%)
Process	–	1 (17%)	3 (50%)	2 (33%)
Compliance	–	1 (17%)	4 (66%)	1 (17%)
Continuity	–	3 (50%)	1 (17%)	2 (33%)
Outcome	1 (25%)	1 (25%)	2 (50%)	–
Communications	–	–	6 (75%)	2 (25%)
Cultural Patterns	–	–	1 (25%)	3 (75%)
Cost	1 (25%)	–	1 (25%)	1 (25%)
TOTAL	2 (5%)	6 (14%)	20 (48%)	14 (33%)

6. Did your group follow the "suggested workshop process"?

	Yes	*No*	*In part*
Access	4 (80%)	–	1 (20%)
Process	4 (67%)	–	2 (33%)
Compliance	1 (17%)	–	5 (83%)
Continuity	3 (50%)	–	3 (50%)
Outcome	1 (25%)	–	3 (75%)
Communications	8 (100%)	–	–
Cultural Patterns	3 (75%)	–	1 (25%)
Cost	1 (25%)	–	3 (75%)
TOTAL	25 (58%)	–	18 (42%)

7. If yes, how would you rate its value in accomplishing the objectives?

	Extremely effective	*Fairly effective*	*Only slightly effective*	*Not at all effective*
Access	5 (100%)	–	–	–
Process	3 (50%)	3 (50%)	–	–
Compliance	1 (17%)	4 (66%)	–	–
Continuity	2 (33 1/3%)	1 (16 2/3%)	1 (16 2/3%)	1 (16 2/3%)
Outcome	–	2 (50%)	–	–
Communications	8 (100%)	–	–	–
Cultural Patterns	1 (25%)	2 (50%)	–	–
Cost	1 (25%)	1 (25%)	1 (25%)	–
TOTAL	21 (57%)	13 (35%)	2 (5%)	1 (3%)

Additional Comments

Arrangements

Only a few comments were addressed to conference arrangements. Three people thought the accommodations were located too far from things to do in free time, one person thought social activities should have been planned, and one suggested a private room to make the reception more conducive to socializing.

Participants

There were seven comments regarding the participants selected, all essentially expressing the feeling that not enough "pure or grassroots" consumers were present to provide a better balance to providers who, by virtue of their positions, "cannot really assume the role of a true consumer." Only two of these people commenting felt specifically that more *poor* consumers should have been involved.

Focus

Several comments were directed toward the focus of the conference. Four people felt that there should have been more emphasis placed upon implementation and defining of specific responsibilities. One person had hoped for discussion of specific criteria for P.S.R.O. programs, but admitted that this was probably not a conference objective. Three people indicated a feeling that there should have been less emphasis on producing a specific document and more on discussion of problems.

Process

Many of the comments concerned process, and most of these were directed toward the last session. Thirteen people felt that the last session should have been longer to facilitate a better blending of workshop products and a more careful refining of the whole document.

Four people thought this session was fragmented and confusing, but offered no better approach. Two people suggested making the first hour of the last session a workgroup "editing hour" before the total group discussion of the document, one person suggested holding the last session after a week's interval, and two people suggested eliminating it altogether. Other suggestions offered by one person each were to utilize evenings as work sessions and to appoint an "outside" recorder instead of asking an active participant to fulfill this role.

There were several comments about the editing of the document before its discussion at the last session. Two people praised the support staff for their work, and seven people felt that the meaning was too changed through editing; however, all but two of these comments came from two workgroups (Process and Cost). Three of these six people also suggested that someone from each workgroup might have been present during the typing to interpret written notes.

General

Assorted positive reactions were expressed by eight people in terms such as:

- "Very worthwhile"
- "Provided an opportunity for meaningful interaction"
- "Conference planners put together an interesting approach"
- "A Vanguard effort in consumerism"
- "Best conference I've attended for its task and production"
- "Same group should follow up, with perhaps another conference"

A final reaction should leave us all with a thought for the future:

"Conferences can leaven and inspire, but results come from work at home."

Additional copies of this publication may be requested from the New Mexico Regional Medical Program, 2701 Frontier N.E., Albuquerque, N.M. 87131. A fee of $1.25 will be charged to cover postage and printing costs.

Chief organizer for this conference, and editor of this document, was James A. Pulver, Director of Public Affairs, New Mexico Regional Medical Program.